PRIFYSGOL BANGOR / BANGOR UNIVERSITY

PRIFYSGOL
BANGOR
UNIVERSITY

Development of the MobQoL patient reported outcome measure for mobility-related quality of life

Bray, Nathan; Spencer, Llinos; Tuersley, Lorna; Edwards, Rhiannon Tudor

Disability and Rehabilitation

DOI:
10.1080/09638288.2020.1741701

Published: 06/11/2021

Peer reviewed version

Cyswllt i'r cyhoeddiad / Link to publication

Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):
Bray, N., Spencer, L., Tuersley, L., & Edwards, R. T. (2021). Development of the MobQoL patient reported outcome measure for mobility-related quality of life. *Disability and Rehabilitation*, *43*(23), 3395-3404. https://doi.org/10.1080/09638288.2020.1741701

Hawliau Cyffredinol / General rights
Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

• Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
• You may not further distribute the material or use it for any profit-making activity or commercial gain
• You may freely distribute the URL identifying the publication in the public portal ?

Take down policy
If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

05. May. 2023

Title page

Title

Development of the MobQoL patient reported outcome measure for mobility-related quality of life.

Authors

Dr Nathan Bray[1,2]*

Dr Llinos Haf Spencer[1,2]

Dr Lorna Tuersley[1,2]

Professor Rhiannon Tudor Edwards[2]

*corresponding author

Affiliations

[1]School of Health Sciences, Fron Heulog, Bangor University, Gwynedd LL57 2EF

[2]Centre for Health Economics and Medicines Evaluation, Ardudwy Hall, Bangor University, Gwynedd LL57 2PZ

Contact details

n.bray@bangor.ac.uk; +447792670053

Abstract (word count: 199)

Purpose: To examine how mobility and mobility impairment affect quality of life; to develop a descriptive system (i.e. questions and answers) for a novel mobility-related quality of life outcome measure. **Materials and methods:** Data were collected through semi-structured interviews. Participants were recruited predominantly from NHS posture and mobility services. Qualitative framework analysis was used to analyse data. In the first stage of analysis the key dimensions of mobility-related quality of life were defined, and in the second stage a novel descriptive system was developed from the identified dimensions. **Results:** Forty-six interviews were conducted with 37 participants (aged 20-94 years). Participants had a wide range of conditions and disabilities which impaired their mobility, including cerebral palsy, multiple sclerosis and arthritis. Eleven dimensions of mobility-related quality of life were identified: accessibility; safety; relationships; social inclusion; participation; personal care; pain and discomfort; independence; energy; self-esteem; and mental-wellbeing. A new outcome measure, known as MobQoL, was developed. **Conclusions:** Mobility and mobility impairment can have significant impacts on quality of life. MobQoL is the first outcome measure designed specifically to measure the impact of mobility on quality of life, and therefore has utility in research and practice to measure patient outcomes related to rehabilitation.

Keywords: Disability; mobility impairment; quality of life; health-related quality of life; patient reported outcomes; qualitative; QALY; preference based measure

Introduction

Mobility impairment is the leading cause of disability in the United Kingdom (UK), accounting for almost half of all reported disabilities [1]. It is estimated that 6.5million people in the UK have some form of mobility impairment [1]. The National Health Service (NHS) supports more than 1.2 million people with long-term mobility needs through the provision of wheelchairs and other assistive mobility technology, spending almost £200million per year on wheelchairs alone [2].

The term assistive mobility technology refers to a wide array of assistive interventions designed to maintain, facilitate and improve independent mobility, including manual and powered wheelchairs; electric scooters; crutches; walking sticks; walking frames; adapted shoes and orthotics; callipers; and prostheses. Although there are many other forms of mobility enhancing interventions, including physical and occupational therapy and surgical interventions such as arthroplasty, assistive mobility technology interventions are some of the most commonly utilised approaches to improving and facilitating mobility for individuals with long-term mobility impairments.

The National Wheelchair Managers Forum's guidance on healthcare standards for NHS posture and mobility services states that cost-effective provision of assistive mobility technology is a key priority [3]:

> *"While Commissioners must ensure adequate funding for the Service, providers must ensure value for money in service provision, and the prescription of equipment that meets the clinical and lifestyle needs of the user in a cost effective manner." [3, p9]*

In order to achieve this, robust economic evidence is required, however to date only limited evidence has been published about the cost-effectiveness of the various forms of assistive mobility technology.

In the economic evaluation of health technologies, the National Institute for Health and Care excellence (NICE) recommends an outcome known as the quality-adjusted life year (QALY) [4], which is derived from preference-based measures of health-related quality of life. QALYs are calculated by multiplying the amount of time spent in a given health state by the relative quality of life of that state. Health states are assigned utilities representing societal health state preferences. As QALYs are generic, they theoretically offer a single metric by which to assess the outcomes of disparate health interventions, but this genericity can consequently cause insensitivity in certain patient groups. For instance, in health states where quality of life takes precedent over quantity of life (e.g. chronic illness, life-limiting conditions and disability), QALYs derived from generic preference-based measures can under value the effectiveness of an intervention [5].

The correlation between generic preference-based measures (such as the EQ-5D, HUI3 and AQoL) and other clinically relevant and condition-specific measures is considered to be moderate at best in common conditions associated with mobility impairment, such as cerebral palsy [6,7,8] and spina bifida [9,10]. Likewise there are reported differences between the health state valuations of different preference-based measures in patient groups with impaired mobility [6,9,11,12]. The evidence suggests a general lack of validity and responsiveness of generic preference-based measures in this context.

This is partly because the relationship between mobility impairment and health-related quality of life is complex. For instance, individuals with long-term mobility impairments indicate that mobility does not have a major impact on their health-related quality of life

when suitable adaptations are available [13,14], and yet general population EQ-5D value sets significantly limit maximum HRQoL when ability to walk is affected, highlighting a narrow definition of mobility.

One of the key issues with generic measures is the apparent lack of appreciation for health state adaptation. When assessing the desirability of hypothetical health states, individuals focus on the transition from their own health state to the hypothetical health state, thus general public beliefs about the impact of diseases and disability does not always reflect the lived experience [15,16]. Focus on personal transition means that processes such as adaptation are not accounted for, causing uncertainty in how states of disability impact outcomes over time [17]. One solution is to improve descriptive systems (i.e. questions and answers on outcome measure) and include wellbeing dimensions which better reflect the lived experience of specific health states [18]. Similarly, condition-specific preference-based measures can be developed to improve sensitivity and relevance.

Over 50 condition-specific preference-based measures have been developed [19], in areas as diverse as visual impairment [20], epilepsy [21] and multiple sclerosis [22]. To date no preference-based measures have been developed specifically to measure outcomes related to mobility impairment and assistive mobility technology use. At present there are several mobility-related outcome measures available to therapists and assistive technology providers. For instance: the Quebec User Evaluation of Satisfaction with Assistive Technology tool [23] evaluates levels of service and assistive technology satisfaction; the Functioning Everyday with a Wheelchair [24] and the Wheelchair Users Functional Assessment [25] tools assess ability to carry out specific tasks and activities relating to mobility; the Psychosocial Impact of Assistive Devices measure [26] focuses on functional independence, well-being and quality of life related to assistive technology use; the Canadian Occupational Performance

Measure [27] focuses on rating patient occupational performance and satisfaction with various aspects of life; and the Wheelchair Outcome Measure [28] and the Wheelchair outcomes Assessment Tool for Children [29] provide patient-centred approaches to identifying and measuring patient outcomes associated with wheelchair use. None of these existing measure are preference-based or focussed specifically on mobility-related quality of life, justifying the need for a novel outcome measure in this context.

Although the causes of mobility impairment are vast and varied, the aim of this research was to define the common areas of mobility-related quality of life which are broadly relevant to most people with limited or impaired mobility. The research reported in this paper is part of a larger project to develop a mobility-related approach to QALY calculation which is sensitive to changes in mobility-related quality of life. The first stage was to develop a novel descriptive system, thus the key objectives were to:

1. Qualitatively examine how mobility and mobility impairment affect quality of life and health.
2. Disaggregate the concept of mobility into the key dimensions of mobility-related quality of life.
3. Develop a descriptive system for a novel mobility-related quality of life outcome measure, known as MobQoL.

Materials and methods

An exploratory descriptive study was undertaken, using a qualitative framework analysis approach. Qualitative data were collected through semi-structured interviews with individuals with varying degrees of mobility impairment, to develop a thematic framework for mobility-related quality of life. This framework was used to disaggregate the concept of mobility into the key dimensions of mobility-related quality of life. Using this data a descriptive system

was developed as the first stage of creating the MobQoL outcome measure. The research was underpinned by principles of disability equality, utility theory, and informed by the World Health Organization's International Classification of Functioning, Disability and Health [30]. Multiple approaches to developing of condition-specific preference-based measures have been documented [19,31]; a "de novo" method was used in this study as there are no existing condition-specific measures which could be adapted into a preference-based measure for mobility-related quality of life. The study was granted ethical approval by an NHS research ethics committee (reference: 17/WA/0072) and an academic ethics committee at Bangor University.

Participants and sampling

Maximum variation sampling was utilised to create a diverse sample of individuals with a wide range of conditions and disabilities which affected their mobility. We focussed predominantly on individuals who currently had or had previously experienced a significant long-term mobility impairment, which necessitated the use of any form of mobility enhancing intervention or assistive mobility technology to enhance, maintain or facilitate independent mobility and/or to reduce complications related to mobility impairments as part of rehabilitative treatment. For the purpose of this research a long-term mobility impairment was defined as any condition, impairment, disability or illness causing impairment to mobility for 12 months or longer; in accordance with the Equality Act 2010 definition [32]. We defined a "significant" mobility impairment as any impairment to mobility which necessitated the use of assistive mobility technology and/or a mobility enhancing intervention to enhance, maintain or facilitate mobility or to reduce complications related to mobility impairments.

As part of the maximum variation sampling frame, attempts were made to establish a broad and varied sample containing individuals with congenital and acquired mobility impairments; progressive and static mobility impairments; and representing all NHS categorisations of mobility need (low, medium, high and complex).

Mobility impairments were purposefully differentiated as acquired or congenital, as the onset of impairment can significantly influence individual adaptation [33]. For instance, individuals with congenital disabilities exhibit higher degrees of life satisfaction, self-identity and self-efficacy than individuals with acquired disabilities [33] - therefore it was expected that these different patient groups would have different insights. Specific disabilities, conditions or functional statuses were not explicitly targeted.

In the interest of establishing a varied sample and including the identification of disconfirming evidence as part of the research design [34], we sought a small number of individuals who had no experience of mobility impairment, or had only experienced a short term impairment resulting from injury.

The sample was stratified by age and categorisation of mobility impairment (long term: acquired; long-term: congenital; short term; no mobility impairment). Due to the broad nature of the sampling frame, eligibility was assessed using a relatively simple set of criteria: aged 18 or older; able to communicate in English or Welsh; and capacity to understand the project and provide informed consent. In one case a participant was unable to provide informed consent, therefore their primary caregiver was invited to participate separately.

Recruitment strategy

Three NHS posture and mobility services and one NHS orthotics department supported recruitment of participants across England and Wales. Eligible patients were sent study

invitation packs by their relevant recruitment site. Participants indicated their willingness to participate in the study by returning a completed demographic questionnaire survey to the research team. In line with good practice all participants were given a £10 high-street voucher as a thank you for taking part; this was not used to coerce participation in the study. At the data collection visit for each participant, informed consent was obtained prior to starting the interview.

Data collection

In order to develop the MobQoL descriptive system, we collected and analysed qualitative data derived from semi-structured interviews. Data collection was divided into two consecutive stages:

- *Stage one - Defining mobility-related quality of life:* Semi-structured interviews were conducted to define the dimensions of mobility-related quality of life; through discussion with participants about how mobility and mobility impairment influence and impact on quality of life and health status.
- *Stage two - Refining the MobQoL descriptive system:* After the development of the key dimensions of mobility-related quality of life, a draft version of the MobQoL descriptive system was produced and presented to participants. Additional semi-structured interviews were conducted, in which participants were asked to discuss the descriptive system, including their understanding of each dimension, the wording of each dimension, the response levels for each dimension and to identify any missing dimensions.

Interviews were conducted in a place of the participant's choosing (most commonly their home) or over the telephone or Skype if a face-to-face meeting could not be arranged. Each

interview lasted about an hour. Separate interview topic guides were created for each stage (see supplemental file 2), and were developed through consultation with relevant patient and professional groups. Field notes supplemented digital recording of the interviews.

Data handling and analysis

Interviews were recorded digitally, transcribed verbatim and anonymised. Qualitative analysis software nVivo (v10.6) was used to manage the data. Data collection and analyses were undertaken in parallel so that analyses could be reflexive to emerging themes within the data.

In stage one qualitative framework analysis was used to organise and synthesise data into analytical themes [35,36]. Framework analysis comprises five key stages; familiarisation, identifying a thematic coding framework, indexing, charting and mapping/interpretation [35,36].

The familiarisation stage was used to develop an *a priori* thematic coding framework, which was then used to line-by-line code all subsequent interview transcripts in the indexing stage. Inductive emergent codes were added to the coding framework as required. Once all interviews were transcribed and analysed, codes were grouped into themes of related codes during the charting stage. Charting consisted of summarising the data into a matrix for each theme, with one row per participant and one column per code. For each theme, participant data was abstracted using verbatim language to summarise each related code. In the final mapping/interpretation stage, conceptual attributes of mobility-related quality of life were finalised by examining relationships between themes, and also by comparing and contrasting data from different participant groups (e.g. by age or onset of impairment).

The final list of conceptual attributes was used to define the dimensions of mobility-related quality of life and subsequently the items (i.e. questions) and item levels (i.e. question response choices) of the MobQoL descriptive system. The wording for each item and item level was finalised after the stage two interviews. In the stage two analysis, transcripts were analysed to identify commons themes regarding item wording, participant understanding of items and the response levels for each item. This was carried out to complement the stage one analysis and to refine the descriptive system items, thus the results for the two analyses were synthesised to produce the final descriptive system. It was initially planned that the levels for each item would be based on the "generic qualifier" scales from the International Classification of Functioning, Disability and Health (ranging from "no problem" to "complete problem") [30], but following completion of the interviews a variety of responses scales were required.

Qualitative research reporting standards

This paper follows the COREQ checklist for qualitative reporting standards [37]. Data collection was carried out by one researcher (NB), and data analysis was carried out by two independent researchers (NB, LH). Wider discussion of the data within the research team and PPI advisory group was used to shape and test interpretations and to ensure internal validity. One participant was known to the research team prior to conducting the interviews. NB and LH are experienced researchers in this context, having jointly conducted several qualitative research studies with people with mobility impairments [29,38,39].

Results

Participant quotes are presented as informative and clear representations of conceptual attributes. Irrelevant information has been replaced with ellipses […] to facilitate ease of reading. Repetitive speech and linguistic fillers (such as "um") have been removed. Where

there is more than one respondent presented in a single quote the following tags have been used for clarity: “R:” for researcher, “P:” for participant, “M:” for mother and “F:” for father. Participant ID numbers are presented so that multiple quotes from the same individual can be identified. To provide context, participants’ age and frequency of assistive mobility technology use are presented for each quote.

Response rate and sample size

A total of 300 study packs were distributed across England and Wales by the four recruitment sites. Forty-seven expressions of interest were returned (initial response rate of 15.7%). Of the 47 individuals invited to take part in an interview, 4 withdrew from the study before taking part in an interview, 5 did not respond to repeated interview invitations and 1 could not speak English. In total 37 participants were interviewed in stage one, giving a secondary response rate of 78.7%. Nine participants were re-interviewed in stage two. An overall interview response rate of 12.3% (n=37) was observed for all of the 300 study packs sent out.

Demographic details are presented in full in table 1. Within the sample, ten participants had long-term mobility impairments resulting from congenital conditions; 19 had long-term mobility impairments acquired later in life due to a condition or disease; 3 had long-term mobility impairments due to acquired spine or brain injury; 4 had experience of a short-term mobility impairment due to musculoskeletal leg injury; and 1 participant had no experience of impaired mobility. Of the sample, 34 participants (92%) currently used at least one mobility aid; the most common primary mobility aids were manual wheelchairs (n=11) and powered wheelchairs (n=11). For the participants who used mobility aids, half (n=17) used assistive mobility technology “all of the time” and 59% (n=20) had adapted their home to increase accessibility. On average, participants had been using mobility aids for 11years (SD=9).

[Insert table 1 near here]

Defining mobility-related quality of life and the MobQoL descriptive system

In total, 11 conceptual attributes were derived from the data and used to define the dimensions of mobility-related quality of life. These comprised 46 sub-themes, see table 2 for full details. Despite relating to an overarching dimension, certain sub-themes within the data were also conceptually rich in their own right. Three dimensions were therefore divided into their component sub-themes to acknowledge the conceptual similarities and differences of the sub-themes. These dimensions were mental wellbeing (comprising the expanded sub-themes of mood/emotions, frustration and anxiety); participation (comprising the expanded sub-themes of activities and contribution) and accessibility (comprising the expanded sub-themes of accessibility at home and accessibility in the wider community).

[Insert table 2 near here]

The dimensions and their relevant sub-themes were used to develop a draft descriptive system, which was refined using the stage two interviews. The product of the two stages of interviews was the finalised MobQoL outcome measure (see assistiveemental file 1). The MobQoL descriptive system comprises 15 items, which relate to the 11 dimensions of mobility-related quality of life. Feedback on the descriptive system was sought from patient and public involvement (PPI) representatives, relevant clinical experts and expert advisors, which led to minor adjustments to the wording of items to improve readability. The synthesised findings from the two stages of data collection are presented below. Each of the dimensions is described in detail, with illustrative participant quotes, and indications where data from the stage two interviews was used to refine the related descriptive system item:

1. *Accessibility*

The ability to access both public and private spaces was perceived by most participants to have a significant influence on quality of life, as accessibility governed ability to participate in valued activities. Participants described issues in accessing both private and public spaces, and the need for physical adaptation to environments to promote accessibility. This was particularly important for individuals with larger mobility aids, such as wheelchairs and scooters, who felt that public spaces in particular were often too small to adequately accommodate their form of mobility. Participants discussed the importance of being able to adapt in order to promote mobility and good quality of life. For many participants adaptation of the physical environment was key to promoting and facilitating movement; in situations where access was limited, participants described feelings of frustration and isolation.

> *P024: "You go somewhere thinking you're going to be able to go in and potter, and all of a sudden, it's like the door gets closed. 'That's thrown me, change of plan. Where can we go?' What do you do, now? The building's access is considerably poor. Very poor. Curbs for wheelchairs? Nightmare. Trying to get up and down. Cars being allowed to block any ramp that's put there." [59 year old; use of assistive mobility technology 'a little of the time']*

During the phase 2 interviews, participants noted that access within and outside of the home were two separate issues, as individuals can to some extent control and adapt accessibility within the home but not outside of the home. An individual's mode of mobility can also vary in and out of the home. This was taken into account in refining the descriptive system, thus accessibility was separated into two sub-themes: a) accessibility at home, and b) accessibility in the wider community

2. Safety

Several participants discussed the impact of unsafe movement, including issues around steadiness, balance, falling and abnormal gait. Participants expressed concern about the risk of accidents and injury resulting from their mobility.

> *P002: "Well, all I can do is walk around in this house. I can't go outside, I'm frightened of falling…it's fear with me. I'm petrified of falling or something." [68 year old; use of assistive mobility technology 'most of the time']*

Concerns about safety related to both the act of moving and the impact of the environment on movement. For instance, uneven terrain was often perceived to increase the risk of accident or injury. Participants experienced safety issues with and without the use of mobility aids; several participants described circumstances where mobility aids contributed to unsafe movement, such as unstable wheelchairs. Some participants described hypervigilance resulting from accidents, and ongoing anxiety which impacted on their daily lives.

> *P039: "Even though you have the mobility aids, sometimes the fear barrier is a really big thing to get over. When you go out, the risk is there. You're on your own and you might fall or stumble." [60 year old; use of assistive mobility technology 'all of the time']*

3. Relationships

Many participants described the importance of support from family and friends to help them cope with impaired mobility. Some participants described feeling like a burden on their family, as they relied on familial support to move around and complete everyday tasks. For some participants this led to feelings of shame and guilt.

P002: "I get frustrated that I have to keep asking people to do things for me…It gets me really down. [My daughter] has enough with her children, and I'm saying, 'Can you do this for me?'…I feel sorry for them that I'm having to rely on other people to do things for me." [68 year old; use of assistive mobility technology 'most of the time']

Mobility impairment was often seen as an inhibitor to social interaction due to limitations of access and participation, which affected the maintenance of friendships. Mobility aids were commonly relied on to counteract the restrictions of mobility impairment and promote social interaction, although several participants could not access the homes of other people because they were not sufficiently adapted for their assistive mobility technology.

M033: "What we try to do is go out, but we can't go out so we're stuck. Especially given that a lot of people's houses have steps, so we feel extremely excluded from the rest of the family. Extremely." [mother of 21 year old; use of assistive mobility technology 'all of the time']

Participants expressed feelings of isolation and loneliness due to the limitations of their mobility, particularly individuals who were predominantly housebound. Social media was used by some participants in order to substitute in-person interaction and to seek peer support from individuals with similar experiences. Some participants stated that family and friends found it hard to understand and empathise with their experience of disability, particularly for individuals with "invisible" conditions.

P007: "My condition, you can't see it. It then becomes impossible for people to understand what your problems are. Even my own family, it's so difficult for them because every day I am in excessive pain but I block it. I put it in a box." [62 year old; use of assistive mobility technology 'all of the time']

4. Social inclusion

Mobility impairment was persistently seen as having a detrimental impact on an individual's ability to participate in wider society, in part due to the social stigma of disability and the impact on an individual's ability to adequately engage in certain activities and social situations. Some participants felt that their mobility aids acted as a negative symbol of their disability, and thus contributed to their feelings of marginalisation, embarrassment and social exclusion.

> *P013: "I realised looking around me, the minute you sat in a wheelchair, you disappeared in a lot of people's eyes. You just weren't there anymore." [56 year old; use of assistive mobility technology 'most of the time']*

Many participants described situations where they were ignored, patronised or victims of prejudice/discrimination because of their mobility impairment or disability. In some instances this led to anxiety and concerns about going out in public.

> *P007: "I've had a few people saying, 'What are you doing on that [scooter]?' Older people. They're all older people."*
>
> *R: "How does it make you feel?"*
>
> *P007: "Oh, dreadful. Absolutely dreadful. It's like you don't want to go out. You're not classed the same as anybody else. Which I strive to do, to be the same." [62 year old; use of assistive mobility technology 'all of the time']*

5. *Participation*

Participation in valued activities was a common theme, as many participants felt that their participation in leisure, work and domestic activities was restricted because of their mobility. Participation was subdivided into two separate sub-themes: activities and contribution

Activities: Most participants discussed the impact of mobility on their ability to do the activities that are important to them. Mobility influenced the behaviours of participants, as they commonly allowed perceptions about their mobility to govern what activities they would and would not participate in. The concept of activity participation included social interaction, hobbies, sport and family life. How individuals defined the concept of activity participation varied greatly depending on personal interests, level of mobility and other personal circumstances. Many participants described feelings of frustration, resentment, and sadness due to participatory restrictions resulting from mobility impairment.

> *P032: "Loss of spontaneity…You've got to plan and think about everything. You just can't decide you're going to go somewhere or do something. As I've found over the years, when you get there, you can't do what you want to do."*
>
> *R: "So would you say that it affects what activities you choose to do?"*
>
> *P032: "Totally. Completely. My life is controlled by my lack of mobility. Definitely." [48 year old; use of assistive mobility technology 'some of the time']*

Contribution: Several participants noted that mobility influenced their ability to contribute and participate in productive activities. For some individuals this was centred around family life, such as contributing to household chores and family activities, while for other participants contribution centred around work or social commitments. Contribution was also described in relation to creativity and more broadly relating to feelings of value, usefulness

and helplessness. Some participants with acquired or deteriorating mobility impairments described important transitional periods, where they had to redefine their roles and find new ways to be productive and to contribute.

R: "You mentioned your charity work. Is productivity and feeling like you're able to be productive and to do things you want to do something that's important to your quality of life?"

P024: "Yes. Extremely. That was the thing that brought me back from the brink. It gives you -. You're helping people, but it gives you self-value. I was sitting here with no direction in life, just breathing. No purpose in life. 'What is the point of me existing?' That's where I'd got to. Now I have that purpose. I have something to – I know it sounds wrong- but fight for." [59 year old; use of assistive mobility technology 'a little of the time']

This theme was originally labelled as "productivity", however participant feedback from the stage two interviews indicated that "contribution" would be an easier term to understand and interpret.

6. *Personal care*

Participants discussed a range of topics relating to personal care, including washing, dressing, using the toilet, eating/drinking and arranging care from others. Feelings of dignity, self-reliance and control were commonly associated with personal care. Mobility and ability to transfer were seen as important factors which influenced the extent to which an individual could manage their own care independently.

F038: "I would say that would've been the major change in the electric [wheelchair], was the freedom of choice to go along for his dinner when he knows it's dinner time,

rather than waiting for somebody to come and push him. He can now go into the bathroom independently and have a wee in the urinal and support himself. He was incontinent when he came here. So it has given him so much freedom." [father of 33 year old; use of assistive mobility technology 'all of the time']

Some of the participants with congenital and long-term disabilities were accustomed to accepting support with their care, thus the conceptualisation of personal care varied based on level of mobility, personal ability and past experience. The role of aids and other individuals in personal care did not necessarily have a detrimental impact on quality of life; change to personal care routine appeared to be the most influential factor.

P032: "I've got to be honest, the carers, we moan and groan about the care company from time to time, but if they weren't about and able to assist me with my cleaning and dressing, that would massively affect my quality of life." [48 year old; use of assistive mobility technology 'some of the time']

7. Pain and discomfort

A majority of participants discussed the role of pain, discomfort and posture in movement. Pain was both caused by and a reason for mobility impairment, and thus was an important limiting factor in movement. Participants described how pain could influence the choices they made with regards to their movement, for instance how far they chose to move or the method of mobility they chose. Participants noted that mobility aids, in particular wheelchairs, could improve mobility whilst simultaneously causing pain and discomfort through poor posture and support, thus some participants stated that there was a balance between managing pain and promoting mobility.

P023: "Because I have a lot of pain and I hurt all over, our pavements are not exactly – so I'm jolted all the time. So I don't go out on exploratory ramblings, as I rather hoped I would... I can't self-propel because my arms hurt too much. I can't go too far because being bounced around hurts too much. I can't get on the bus because being bounced around hurts too much. It is a serious issue for me." [62 year old; use of assistive mobility technology 'most of the time']

8. Independence

Independence was an important factor for most participants. Participants stated that independence and independent movement related to feelings of freedom, control and choice, and linked directly to their ability to be mobile. For instance, mobility impairment was commonly related to loss of autonomy/control and feelings of helplessness, particularly for participants with acquired impairments. Most participants with impaired mobility felt restricted by their mobility, which in turn affected their sense of independence and increased their reliance on others. Although assistive mobility technology were generally seen as promoting independence, they could also restrict participation in certain situations due to issues around accessibility and control of movement.

P008: "The times I have to use the manual wheelchair, I try and avoid that at all cost because, I don't know, I can't -. If going around a shop, I couldn't enjoy going around because I feel, I don't know, (.) it's difficult to say. I just don't like the feeling. I feel useless. I suppose it's because I'm dependent on somebody else pushing me around and I've got no control of what I look at, really. So, I mean, definitely try to avoid the manual wheelchair, whereas I'm quite happy on the scooters." [64 year old; use of assistive mobility technology 'some of the time']

How individual's defined independence varied, and appeared to be influenced by their experience of mobility impairment; for instance many individuals with acquired or deteriorating mobility impairments had to redefine independence in accordance with their changing mobility.

> *P017: "I've always been fiercely independent. As soon as I could, I was out getting a job, doing what I wanted to do. And when your body goes, 'Nah, you're not allowed to do that today,' you're like, 'Why? Why not? That's not fair!'" [23 year old; use of assistive mobility technology 'some of the time']*

9. *Energy*

Participants stated that mobility was related to both mental and physical energy. Without adequate physical energy and stamina, participants found that movement was limited or restricted; conversely, inefficient mobility also led to fatigue and exhaustion. Some participants described the impact of mobility impairment on mental energy, leading to reduced concentration, focus and motivation as a result of physical exhaustion.

> *P007: "I try to go out every day because I only have a short window of energy and it's between 12 and four in the afternoon. After that, I drop and I'm in bed at eight, now, and I never used to go to bed this side of midnight. But my body just goes. I've exhausted myself. I might not do much while I'm out but I come back absolutely exhausted and I have to sit." [62 year old; use of assistive mobility technology 'all of the time']*

Participants noted that mobility aids could help to reduce the energy burden of movement, and promote more efficient means of mobility.

10. Self-esteem

Many participants, particularly those with acquired mobility impairments, described a process of "coming to terms" with changing mobility, and the ongoing behavioural and emotional adaptation associated with changes to their mobility and health. This process of developing a new sense of self and identity could be traumatic and detrimental to self-esteem.

> *P031: "I'm a broken person, now. And living with brokenness is a learning curve…I know that when you go to do something, there's certain steps you put in place to get there, psychologically as well as physically. And psychologically, I found it very difficult to arrive there. I found there's a lot more sense of unworthiness, I distrust myself, I haven't got the confidence to do something." [60 year old; use of assistive mobility technology 'a little of the time']*

The level of behavioural adaptation associated with mobility impairment varied, as individuals with acquired or deteriorating conditions often had to adapt their previous behaviours and learn news way to move around. For these individuals in particular, emotional adaptation and the process of coming to terms with their changing mobility had an important influence on their quality of life. Where there was a disparity between identity, behaviour and mobility, participants identified significant impacts to their quality of life.

> *P019: "I'm still not used to it. I try and avoid it. I don't know whether you ever did it, but when we were young, we used to drive through [city name], look at yourself in the car when you go past. See the wheelchair. As long as I can't see it, I can cope with it. But as soon as I see it, it's one of those, 'Why me?' things. It becomes a negative." [59 year old; use of assistive mobility technology 'all of the time']*

11. Mental wellbeing

Participants commonly described the impact of mobility on their emotions and mental wellbeing. These impacts fell under three separate sub-themes: mood and emotions; frustration; and anxiety:

Mood and emotions: The loss or deterioration of mobility was perceived to have a detrimental impact on mental and emotional wellbeing, leading to grief, sadness and even depression. For many participants, feelings of embarrassment, indignity and shame accompanied mobility impairment and the consequential need for additional support from other people.

> *P032: "It's not something I've got over. I still get days when I'm extremely depressed because I can't go and do what I want to do because of my lack of mobility…when you've had all this independence and mobility and then it's gradually over the course of a couple of years taken away from you. It makes you very bitter." [48 year old; use of assistive mobility technology 'some of the time']*

Several participants described a sense of grief and melancholy for their previous selves, and the sadness related with feeling isolated or restricted by their mobility.

> *P027: "It's a massive emotional bereavement and then it's a rebuilding of all your outlook on life." [45 year old; use of assistive mobility technology 'a little of the time']*

This theme was originally labelled as "sadness", however feedback during the stage two interviews indicated that "mood and emotions" would be more appropriate. Participants felt that some individuals would not identify specifically with the concept of sadness; participants suggested using words such as "low", "down" or "unhappy" within the descriptive system to increase coherence.

Frustration: Participants frequently referred to frustration and anger resulting from mobility impairment. Frustration was often related to the restrictions placed upon individuals due to impaired mobility, and the resulting impact on their functioning in everyday life. Many participants reported frustration and resentment at needing to ask other people for help, and at having to find new ways to participate and undertake daily activities. Participants expressed frustration with themselves and at the world around them.

> *P001: "I can't do now what I used to do a couple of years ago and it's frustrating because you have to ask somebody to do it. You know you can do it, but if you try and do it, then it takes twice as long." [54 year old; use of assistive mobility technology 'all of the time']*

Anxiety: Concern about the progression of underlying conditions and subsequent loss of mobility were common causes of anxiety, worry and stress for participants. Uncertainty about the future and everyday management of mobility impairment were also described as significant sources of anxiety.

> *P008:" The more disabled and immobile you become, the more your emotions do get worse…The more you have a slightly less-optimistic view about the future." [64 year old; use of assistive mobility technology 'some of the time']*

Participants worried about the practical experience of mobility impairment, for instance arranging support and coping financially. Several participants found that living with a mobility impairment led to excessive planning and vigilance, which in turn contributed to their anxiety and stress, particularly when attending new environments and activities.

> *P003: "Anxiety issues. Like a friend said, 'There's this new theatre opened. Let's go.' Immediately, I'm thinking, give me the email information. I thought, 'I've got to do so*

much planning before we go,' about accessibility, parking. So that causes anxiety." [44 year old; use of assistive mobility technology 'most of the time']

Discussion

This paper describes the development of a novel mobility-related quality of life outcome measure, known as MobQoL. The intention is that the MobQoL outcome measure will be developed into a preference-based measure, this paper describes the first stage of this process and further work is now needed to pilot the questionnaire and to develop a preference-based scoring system.

The qualitative findings illustrate the ways in which mobility can impact many areas of quality of life, wellbeing and health. Many participants discussed the emotional impact of mobility impairment and the role of adaptation in coming to terms with changes to mobility; similar findings were found in previous research with children [38]. Adaptation is an important process which includes emotional, physical and behavioural changes, and without proper adaptation quality of life can be severely impacted by changes to mobility [33].

At present no generic preference-based measures take full account of the impact of mobility on quality of life, or the influence of adaptation on subsequent health state preferences. For instance, there is limited correlation between three of the most commonly used generic preference-based measures (EQ-5D, HUI3 and AQoL) and other clinically relevant outcome measures [6,7,8,9,10]. Furthermore, there are significant discrepancies between the health state valuations of theses common measures in patient groups with impaired mobility [6,9,11,12].

The MobQoL questionnaire differentiates from existing preference-based measures as it focusses on how health status and quality of life relate specifically to mobility. The

distinction is that MobQoL avoids a normative definition of mobility (i.e. walking), and incorporates all of the key dimensions of health and quality of life which are impacted by mobility and immobility.

The experience of mobility is subjective, thus an individual with impaired mobility does not necessarily experience significantly reduced quality of life if they are able to adapt physically, emotionally and/or behaviourally [13,14]. This distinction is important, as adaptation to health states plays an important role in quality of life, but is not routinely considered in preference-based measure health state valuation. Therefore, generic preference-based measures and subsequent health state valuations derived from the general population may have limited relevancy to the lived experience of chronic conditions and disabilities [15,17].

The MobQoL descriptive system is designed to be answered by an individual in their current state of mobility, so factoring in the use of any aids they currently use. The objective is for the tool to be relevant for any individual whose mobility has been impaired, but it is predominantly focussed on long-term mobility impairment. The descriptive system has been designed so that health states are not necessarily lower due to mobility aid use, to reflect that for many individuals with long-term mobility impairments decreased mobility aid use (or increased walking) is not necessarily an optimum state. This reiterates that it is the impact of mobility on the key dimensions of mobility-related quality of life which is of most importance, regardless of means of mobility.

Mobility is affected by a range of personal and external factors. Personal factors may include limitations to physical functioning, movement, ambulation and balance resulting from injury, impairment or illness. These limitations may be short-term or long-term and the extent to which mobility is impacted by these factors can be extremely variable. External factors which

affect mobility can be further classified into factors which can and cannot be controlled. For instance, an individual has some control over the adaptation of their home environment, but less control over the accessibility of public spaces. The MobQoL outcome measure attempts to cover all of these factors, by including items relating to accessibility in and outside of the home, safety of movement and personal factors relating to self-esteem and mental wellbeing. Three dimensions included in the MobQoL outcome measure have been divided into their component sub-themes. Participant discourse relating to the dimensions of mental wellbeing, participation and accessibility demonstrated that additional sub-themes were necessary to fully capture the importance of specific factors encompassed within these overarching dimensions.

Specific questions about aids, adaptations and devices have been avoided to increase the relevancy of the questionnaire for people in various states of mobility. PPI and expert feedback indicated that the dimensions chosen were reflective of the ways in which mobility (and mobility aids) influence health and quality of life in both positive and negative ways.

In the interest of transparency, it is important to acknowledge the limitations of this research. Due to sample demographics and the relatively small sample size we cannot be certain that the findings are relevant or generalisable to all people with limited or impaired mobility. We attempted to maintain relevance and generlisability by using maximum variation sampling, specifically seeking disconfirming cases and seeking feedback from our PPI advisors. This allowed a broad spectrum of voices and opinions to contribute to the development of the descriptive system. Due to time constraints participants were not involved in analysis and did not have the opportunity to verify transcripts, which may have affected the credibility of the findings. All interviews were transcribed verbatim and analysed by two researchers, thus we are confident in the accuracy of the data. Finally, we acknowledge that the MobQoL

descriptive system is long, with 15 items representing 11 dimensions of mobility-related quality of life. This will increase the complexity of the valuation of all individual health states derived from the measure. Therefore, during the next stage of the outcome measure development project, psychometric testing will be used to identify redundant items and potentially reduce the number of items accordingly. All dimensions of mobility-related quality of life identified from this research have been included in the descriptive system, as there was no clear justification for limiting the scope of the questionnaire at this stage. Some of the dimensions appear to overlap, such as personal care and independence, but were also sufficiently distinct to warrant separate items in the descriptive system.

The benefits of condition-specific preference-based measures include lower patient burden, greater relevancy and lower risk of ceiling effects; conversely they lack comparability across different patient groups, they may underestimate or miss the impact of side effects/comorbidities and they can exaggerate outcomes [40]. Generic measures are useful for comparability across patient groups, but can lack sensitivity, relevancy and responsiveness in certain patient groups and have a higher risk of ceiling effects [31,40]. Thus, it is anticipated that MobQoL and existing generic preference-based measures could be used for somewhat different but complimentary purposes. The choice of measure should therefore take account of the advantages and disadvantages of the two approaches in a given population. Whether utility outcomes generated from generic and condition-specific preference-based measures are comparable is still very much up for debate [40], but there are differences between such QALY estimates. Both approaches to utility measurement can therefore be used in a single study to compare outcomes derived from different approaches to preference-based outcome measurement.

Although many outcome measures exist for the assessment of wheelchair and mobility aid provision [41], MobQoL is the first outcome measure developed specifically to assess the impact of mobility on quality of life. It is also the first attempt to develop a preference-based measure which is specifically designed to be sensitive to changes in mobility arising from assistive mobility technology use and mobility enhancing interventions. The next stage of the project will be to pilot the measure. Our aims in piloting the measure will be to assess the psychometric properties of the MobQoL outcome measure, including: validity, reliability, and sensitivity; and to determine whether there are any redundant items which could be removed from the MobQoL outcome measure.

Acknowledgements

This work was funded by the Welsh Government through Health and Care Research Wales. The funding body had no role in the design, conduct or reporting of this work. The authors would like to thank Professor Joanna Coast, Professor Katherine Payne, Professor Deborah Fitzsimmons, Dr Hareth Al-Janabi and Professor Paul Brocklehurst for acting as expert advisors to the project. The authors would like to thank Emma Bray for transcribing the interviews.

Declaration of interests

The authors report no conflicts of interest.

Abbreviations

MobQoL	Mobility and quality of life outcome measure
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
PPI	Patient and public involvement
QALY	Quality-adjusted life year
UK	United Kingdom

References

1. Department for Work and Pensions. Family resources survey 2017/2018. London: Department for Work and Pensions; 2019.
2. NHS Improving Quality. Right chair, right time, right now. London: NHS Improving Quality; 2014.
3. National Wheelchair Managers Forum. Healthcare standards for NHS commissioned wheelchair services. London: National Wheelchair Managers Forum; 2015.
4. National Institute for Health and Care Excellence (NICE). Guide to the Methods of Technology Appraisal. London: NICE; 2013.
5. Pettitt DA, Raza S, Naughton B, et al. The limitations of QALY: A literature review. J Stem Cell Res Ther. 2016;6:334.
6. Young N, Rochon T, McCormick A, et al. The health and quality of life outcomes among youth and young adults with cerebral palsy. Arch Phys Med Rehabil. 2010;91(1):143–148.

7. Livingston MH, Rosenbaum PL. Adolescents with cerebral palsy: Stability in measurement of quality of life and health-related quality of life over 1 year. Dev Med Child Neurol. 2008;50(9):696–701.
8. Rosenbaum PL, Livingston MH, Palisano RJ, et al. Quality of life and health-related quality of life of adolescents with cerebral palsy. Dev Med Child Neurol. 2007;49(7):516–521.
9. Young NL, Sheridan K, Burke TA, et al. Health outcomes among youths and adults with Spina bifida. J Pediatr. 2013;162(5):993–998.
10. Sims-Williams HJ, Sims-Williams HP, Mbabazi Kabachelor E, et al. Quality of life among children with spina bifida in Uganda. Arch Dis Child. 2017;102(11):1057–1061.
11. Usuba K, Oddson B, Gauthier A, Young NL. Changes in gross motor function and health-related quality of life in adults with cerebral palsy: An 8-year follow-up study. Arch Phys Med Rehabil. 2014;95(11):2071–2077.
12. Bray N, Noyes J, Harris N, et al. Measuring the health-related quality of life of children with impaired mobility: Examining correlation and agreement between children and parent proxies. BMC Res Notes. 2017;10(1):1–8.
13. Burström K, Bartonek A, Broström EW, et al. EQ-5D-Y as a health-related quality of life measure in children and adolescents with functional disability in Sweden: testing feasibility and validity. Acta Paediatr. 2014;103(4):426–435.
14. Bartonek A, Saraste H, Danielsson D. Health-related quality of life and ambulation in children with myelomeningocele in a Swedish population. Acta Paediatr. 2012;101:953–956.

15. Ubel P.A., Loewenstein G., Jepson C. Whose quality of life? A commentary exploring discrepancies between health state evaluations of patients and the general public. Qual Life Res. 2003;12:599–607
16. Dolan P, Kahneman D. Interpretations of utility and their implications for the valuation of health. Econ J. 2008;118:215–234.
17. Versteegh MM, Brouwer WB. Patient and general public preferences for health states: A call to reconsider current guidelines. Soc Sci Med. 2016;16:16–74.
18. Brazier J, Rowen D, Karimi M, et al. Experience-based utility and own health state valuation for a health state classification system: why and how to do it. Eur J Health Econ. 2018;19(6):881–891.
19. Goodwin E, Green C. A Systematic Review of the Literature on the Development of Condition-Specific Preference-Based Measures of Health. Appl Health Econ Health Policy. 2016;14(2):161-183.
20. Misajon R, Hawthorne G, Richardson J, et al. Vision and quality of life: the development of a utility measure. Invest Ophthalmol Vis Sci. 2005;46(11):4007–4015.
21. Mulhern B, Rowen D, Jacoby A, et al. The development of a QALY measure for epilepsy: NEWQOL-6D. Epilepsy Behav. 2012;24(1):36–43.
22. Goodwin E, Green C. A quality-adjusted life-year measure for multiple sclerosis: developing a patient-reported health state classification system for a multiple sclerosis-specific preference-based measure. Value Health. 2015;18(8):1016–1024.
23. Demers L, Weiss-Lambrou R, et al. The Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST 2.0): An overview and recent progress. Technol Disabil. 2002;14:101–105.

24. Mills T, Holm MB, Trefler E, Schmeler M, Fitzgerald S, Boninger M. Development and consumer validation of the Functional Evaluation in a Wheelchair (FEW) instrument. Disabil Rehabil. 2002;24(1-3):38–46.
25. Stanley RK, Stafford DJ, Rasch E, et al. Development of a functional assessment measure for manual wheelchair users. J Rehabil Res Dev. 2003;40(4):301–307.
26. Day H, Jutai J. Measuring the Psychosocial Impact of Assistive Devices: the PIADS. Can J Rehabil. 1996;9(2):159–168.
27. Cusick A, McIntyre S, Novak I, et al. A comparison of goal attainment scaling and the Canadian occupational performance measure for paediatric rehabilitation research. Ped Rehabil. 2006;9(2):149–157.
28. Mortenson WB, Miller WC, Miller-Pogar J. Measuring wheelchair intervention outcomes: Development of the Wheelchair Outcomes Measure. Disabil Rehabil Assist Technol. 2007;2(5):275–285.
29. Tuersley L, Bray N, Edwards RT. Development of the Wheelchair outcomes Assessment Tool for Children (WATCh): A patient-centred outcome measure for young wheelchair users. PLoS ONE. 2018;13(12):e0209380.
30. World Health Organization. The international classification of functioning, disability and health. Geneva: World Health Organization; 2001.
31. Brazier JE, Rowen D, Mavranezouli I, et al. Developing and testing methods for deriving preference-based measures of health from condition-specific measures (and other patient-based measures of outcome). Health Technol Assess. 2012;16(32):1–113.
32. Office for Disability Issues. Equality Act 2010 guidance: Guidance on matters to be taken into account in determining questions relating to the definition of disability. London: Office for Disability Issues; 2011.

33. Bogart KR. The role of disability self-concept in adaptation to congenital or acquired disability. Rehabil Psychol. 2014;59(1):107–15.
34. Antin TMJ, Constantine NA, Hunt G. Conflicting discourses in qualitative research: The search for divergent data within cases. Field Methods. 2015;27(3):211-222.
35. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess R, editors. Analysing Qualitative Data. London: Routledge; 1994. p.173-194.
36. Ritchie J, Lewis J. Qualitative research practice: a guide for social science students and researchers. 2nd ed. London: Sage; 2013
37. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Iny J Qual Health C. 2007;19(6):349–357.
38. Bray N, Noyes J, Harris N, et al. Defining health-related quality of life for young wheelchair users: A qualitative health economics study. PLoS One 2017;12(6):e0179269.
39. Noyes J, Spencer LH, Bray N, et al. Conceptualization of physical exercise and keeping fit by child wheelchair users and their parents. J Adv Nurs. 2017;73(5):1111-1123.
40. Rowen D, Brazier J, Ara R, et al. The Role of Condition-Specific Preference-Based Measures in Health Technology Assessment. PharmacoEconomics. 2017;35(Suppl 1):33-41.
41. Kenny S, Gowran R. Outcome measures for wheelchair andseating provision: a critical appraisal. Br J Occup Ther. 2014;77(2):67-77.

Tables

Table 1: Demographic details for participants included in the study

Age	
	N(%)
18-24 years	7 (18.9)
25-34 years	6 (16.2)
35-44 years	3 (8.1)
45-54 years	4 (10.8)
55-64 years	13 (35.1)
65-74 years	3 (8.1)
75+ years	1 (2.7)
Gender	
Female	20 (54.1)
Male	17 (45.9)
Employment status	
Full-time	2 (5.4)
Part-time	3 (8.1)
Unemployed	5 (13.5)
Student	4 (10.8)
Full-time parent/carer	2 (5.4)
Long-term sick leave	8 (21.6)
Retired	12 (32.4)
Did not answer	1 (2.7)
Primary reason for impaired mobility	
Cerebral palsy	6 (16.2)
Multiple sclerosis	5 (13.5)
Arthritic condition[1]	5 (13.5)
Musculoskeletal injury[2]	4 (10.8)
Spine or brain injury[3]	3 (8.1)
Myalgic encephalomyelitis	2 (5.4)
Other[4]	11 (29.7)
No mobility impairment	1 (2.7)
Primary mobility aid*	
PWC	11 (32.4)
MWC	11 (32.4)
Walking stick/crutches	5 (14.7)
Mobility scooter	3 (8.8)
Other[5]	4 (11.8)
Frequency of mobility aid use*	
A little of the time	5 (14.7)
Some of the time	4 (11.8)
Most of the time	7 (20.6)
All of the time	17 (50.0)

*Sub-sample of individuals who use assistive mobility technology

[1] Osteoarthritis n=3; psoriatic arthritis n=1; rheumatoid arthritis n=1

[2] Osteochondral fracture, dislocated knee, broken ankle, fractured hip (n=1 for all)
[3] Spinal injury n=2; traumatic brain injury n=1
[4] Parkinson's disease, stroke, spina bifida, polymyositis, muscular dystrophy, generalised hypermobility spectrum disorder, Arnold-Chiari malformation, cerebellar ataxia, fallen arches, fibromyalgia, small fibre neuropathy (n=1 for all)
[5] White cane, ankle/knee supports, walking frame, orthotic insoles (n=1 for all)

Table 2: Dimensions of mobility-related quality of life and their sub-themes

Dimensions	Sub-theme
Accessibility	Accessibility at home Accessibility in wider community
Safety	Risk of injury Steadiness Balance Fear of falling
Relationships	Friendship Family Love Peer support Feeling like a burden
Social inclusion	Feeling accepted by society Experience of prejudice and discrimination
Participation	Activities Fun and enjoyment Socialising Achievement Contribution Feeling useful Fulfilling roles
Personal care	Personal hygiene and toileting Eating and drinking Dignity Accepting support and care
Pain and discomfort	Physical pain Posture and discomfort Pain from injury
Independence	Control Freedom Self-reliance Autonomy
Energy	Stamina Fatigue Quality of sleep Concentration and focus Motivation

Self-esteem	Confidence Self-worth Identity Coming to terms with mobility changes Assistive mobility technology a negative symbol of disability
Mental wellbeing	Sadness and depression Frustration Resentment Anxiety and worry Hypervigilance